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# **Advanced Care Planning: an exploratory study of community based mental health practitioners' views and experiences of ACP in practice with people with dementia**

Kevin Goodwin and Jill Manthorpe

## **Purpose**

Advanced care planning (ACP) involves the discussion of preferences relevant to a possible future time when one's ability to make decisions may be compromised. ACP is considered as having potential to enhance choice and control and thereby to improve the experience of care for people with dementia and their carers. Care coordinators have been highlighted as possibly playing a central role in facilitating these discussions among people with long-term care needs. However, there is limited evidence of how ACP is facilitated by community mental health professionals who may be supporting people with dementia and carers.

## **Design/methodology/approach**

This exploratory study took the form of qualitative semi-structured interviews to explore the views and experiences of community mental health professionals when discussing ACP with people with dementia and/or their carers. A convenience sample of 14 participants working in community mental health services in one NHS Mental Health Trust in London, England was recruited and interview data were analysed using a Framework approach.

## **Findings**

Five themes emerged from the interviews - Knowledge and Experience, Use of ACP, Inhibitors of Discussion, Service Influences and The Future. The depth of ACP facilitation appeared dependent on the knowledge, confidence and skills of the individual professional. Limited resources leading to service rationing were cited as a major barrier to ACP engagement. Helping people with dementia and their carers with ACP was not viewed as a priority in the

face of competing and increasing demands. A further organisational barrier was whether ACP was viewed by service managers as 'core business'. Findings indicate that practice was generally to refer people with dementia to other agencies for ACP discussions. However, pockets of ACP practice were reported, such as explaining proxy decision making options for finances.

#### Research limitations/implications

This exploratory study took place in the community mental health services in one NHS Mental Health Trust that may not be representative of other such teams. Case records were not scrutinized or clinical conversations with people with dementia or carers.

#### Practical implications

Barriers to initiating ACP discussions were cited, such as limited resources, lack of time and knowledge; unclear role remit, uncertain service direction and poor documentation sharing processes. However, participants held a common belief that ACP for people with dementia is potentially important and were interested in training, a greater team focus on ACP, and pathway development. This indicates the potential for staff development and continuing professional development.

#### Originality/value

Few studies have asked a wide range of members of community mental health services about their knowledge, skills and confidence in ACP and this study suggests the value of taking a team-wide approach rather than uni-professional initiatives.

**Advanced Care Planning: an exploratory study of community based mental health practitioners' views and experiences of ACP in practice**

## **Introduction and Background**

This exploratory study investigated the perspectives of a sample of professionals working in Community Mental Health Services about undertaking Advanced Care Planning (ACP) with people with dementia and/or their family carers. For an older person with dementia, health will generally decline and disability increase. At end of life individuals often need personal care, have communication and mobility problems, become frail, develop incontinence and difficulties arise with feeding, swallowing, weight loss and pressure ulcers (Alzheimer's Society, 2015). It is hard to predict when someone with dementia reaches the end of life, as the illness trajectory is unpredictable (Denning, Greenish, Jones, Madal & Sampson, 2012) thus person-centred guidelines recommend continued attention to planning (Fazio et al 2018).

People with dementia often receive a poorer quality of end of life care than those without cognitive impairment (Banerjee, 2014). In advanced stages, admissions to hospital are common (Kumar & Kuriakose, 2013), which can be unfamiliar, over-stimulating and distressing environments (Marie Currie & Alzheimer's Society, 2014). Here invasive and often ineffective procedures to prolong life may occur such as Cardiopulmonary Resuscitation (CPR) (BMA, Resuscitation Council (UK) & RCN, 2014). However, overall, the United Kingdom (UK) is considered to have a 'superlative position' in provision of end of life care for its population because of the high level of commitment by the National Health Service (NHS) to develop and implement a comprehensive framework to improve end of life care at national and local levels (Carr and Luth, 2017). Commentators suggest that this gives inspiration to those seeking to incorporate palliative care excellence in the care of people with conditions such as dementia (Rietjens et al 2017).

## **Advanced Care Planning (ACP)**

People may express preferences about what they would and would not like to occur at any future time when they cannot make their wishes known. ACP is described as:

A voluntary process of discussion about future care between an individual and their care providers irrespective of discipline...(which) usually takes place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others (The National End of Life Care Programme, 2008)

In ACP, the individual is informed about their diagnosis, prognosis and care options, while professionals learn of the individual's values, priorities and decisions about care and the future (Glaudemans, Moll van Charante, & Willems, 2015). It is recommended in the latest National Institute of Health and Care Excellence (NICE) guidelines (NICE 2018, para 1.1.12).

Discussions regarding life sustaining treatments may be incorporated (Kumar & Kurikose, 2013). Documentation is not necessary in ACP, although usually completed. Plans should be reviewed and accessible so they can be put in place if the ability to communicate is lost (Royal College of Physicians et al., 2009). There is some evidence that ACP reduces symptoms of post-traumatic stress, anxiety and depression among relatives (Detering, Hancock, Reade & Sylvester, 2010) and Dixon, King and Knapp (2016) found an association between one element of ACP, using the indicator of an expressed preference for place of death recorded by healthcare staff, and a greater likelihood of dying in one's usual place of residence.

The Mental Capacity Act 2005 (MCA) (Department for Constitutional Affairs, 2007), applicable in England and Wales, enables adults with capacity to make future plans through compiling statements of wishes, Advance Decisions to refuse treatment (ADs) or to appoint Lasting Power of Attorney(s) to make decisions on their behalf. ADs (known as Advance Directives in the US and elsewhere) enable an individual to refuse specific treatments, including life-sustaining procedures. These must be documented and are legally binding if valid

and are applicable (unambiguous and relevant) (Alzheimer's Society, 2015). Individuals cannot refuse basic nursing care, such as being cleaned, fed naturally or repositioned (Mullick, Martin & Sallnow, 2013).

Statements of wishes cover an individual's beliefs, values and goals about their future care, such as to remain at home. Although not legally binding, they should be respected and taken into consideration (NICE 2018). ACP may also discuss making a Lasting Power of Attorney (LPA), appointing a proxy to make decisions and manage all or specific issues regarding property and financial affairs and/or health and welfare (including care, end of life care and refusals of specific treatments, if documented) should the individual lose the ability to make such decisions (Alzheimer's Society, 2015).

In the United States (US), the Patient Self-Determination Act 1990 (PSDA) mandates healthcare professionals to inform patients of their rights to make an AD. In England and Wales, there is no such requirement and no central register for ACP documentation other than for LPAs, where the rate of LPA applications is increasing annually. By the end of 2018, over 3.4 million LPAs had been registered (Office of the Public Guardian (2019)). In respect of other plans, drawing on a survey of 1823 older people, Musa, Seymour, Narayanasamy, Wada, Leary & Conroy (2015) found 13% had prepared a statement of wishes, while 4% had prepared an AD. While 60 per cent would discuss ACP if such a conversation was initiated by others, only 4.6 per cent of those surveyed had been offered this.

Many policy statements stress the importance of individuals with dementia having support to engage in ACP (Department of Health (DH), 2009; The National End of Life Programme, 2010; NICE 2018; Fazio et al 2018). The UK Prime Minister's Dementia Strategy set a target

that everyone with dementia should have such opportunities by 2020 and recognised that care coordinators can play a central role in this (DH, 2015).

### **Community Mental Health Services**

Memory services were established to meet demand for early dementia recognition; commonly providing assessment, diagnosis and treatment, such as medication and monitoring (Willis, Chan, Murray, Matthews & Banerjee, 2009). Patients may also be referred to older adult Community Mental Health Teams (CMHTs) which are part of NHS secondary mental health services offering interventions such as assessment, diagnosis, treatment, monitoring, and care coordination for people with a range of diagnoses including dementia. Patients accepted by a CMHT may be at a later stage of dementia or be referred to them, for example, to assist with distressing behavioural or psychological symptoms of dementia. There is considerable variation between CMHTs in England regarding their operation, professionals involved and length, nature and frequency of contact with older people with mental health problems and their carers (Wilberforce et al., 2015; Manthorpe et al 2018).

#### **Aims:**

This small study aimed to explore the perspectives of a sample of community-based healthcare professionals about ACP. The sample was taken from a convenience sample of professionals working in memory services and in CMHTs who regularly work with people with dementia and their carers. It sought to ascertain in what circumstances these professionals discussed ACP with their clients and ACP case recording. It further aimed to explore what these professionals understand about ACP processes, any ACP experiences, barriers and facilitators of ACP discussions. The aim was to improve understanding of ACP practice in community settings.

### **Methods**

As the aim of this exploratory study was to investigate participants' views and experience of ACP, a qualitative method was employed with use of semi-structured interviews. Purposive sampling was used to specifically select a range of participants who might be able to generate rich information about ACP (Green & Thorogood, 2014). Criteria for involvement were that participants were currently working with people with dementia in either a CMHT or memory service. Letters were sent to four CMHT and three Memory Service managers (who acted as gatekeepers to accessing potential participants) explaining the research purpose and requesting that the Participant Information Sheet be passed to colleagues. This sheet included information about the research purpose, process, how findings would be presented, that all information would be treated confidentially and how to contact the researcher if interested in participating.

A pilot interview was conducted with an initial topic guide for questions. Questions were condensed following the pilot and participants were provided with the short topic guide to follow during the interview. As recommended by Keats (2000), after participants signed the consent form descriptive demographic data were obtained, such as job role, job setting and experience since qualification, followed by a core set of questions to gather information, with use of probing questions, to explore further, enhance or clarify this information. Recordings were transcribed verbatim. Although 15 interviews were completed, due to incomplete recording of the pilot interview, this was not used in the final analysis, leaving 14 transcripts for analysis.

## **Analysis**

As the amount of information gained from qualitative interviewing is often large, unstructured and unwieldy (Bryman & Burgess, 1994), a system is needed to analyse and present important findings. Framework analysis (Ritchie & Spencer, 1994) was developed for applied policy research to provide specific information and actionable outcomes. It uses five visible, distinct



but interconnected stages- familiarisation, identification, indexing, charting and mapping and interpretation in order to systematically synthesize and interpret data and enhance rigor, although it also requires creativity on the part of the researcher to detect concepts, meaning and connections within the data.

Familiarisation is the repeated reading of interview transcripts, immersing oneself in the data to gain an overview of its range. Identification involves making notes of recurrent themes and important points, making judgements of meanings and key concepts to create an index.

Indexing is the process of systematically applying this index to each transcript. Charting involves lifting data from transcripts and according to themes, grouping this together in charts, allowing comparisons between and within participants. Five main themes (outlined below) emerged which were charted. Mapping and interpretation helped to locate patterns, associations, concepts, or explanations.

When interviewing participants about potentially sensitive topics, there is potential of arousing feelings of distress (Moriarty, 2011). It was possible that participants may have engaged in ACP at a personal or family level or had experiences or beliefs that could affect the interview or that they might feel under scrutiny. To help participants to feel at ease and to build rapport, participants were advised, prior to interview, that they could decline to answer any question if they wished and interviews took place at a location of their choosing. Ethical approval was granted for this research from (anonymised) and the NHS Trust where the research took place is not named.

## **Findings**

Participants interviewed included Doctors, Community Psychiatric Nurses (CPNs), and a small number of Social Workers (SWs) and Occupational therapists (OTs) (see Table 1). To

minimise the risk of identification of the SWs and OTs these are referred as HPCP registrants, the Health and Care Professions Council (HCPC) being the name of their shared regulator at the time. Twelve of the 14 participants undertook Care Coordination and two Case Management roles.

Through Framework analysis, five separate but interconnected themes emerged - **Knowledge and Experience, Use of ACP, Inhibitors of Discussion, Service Influences** and **The Future**.

**Table 1: Participant Demographic Information (n=14)**

Age Range - 28-58 years

Gender

Male 3

Female 11

Profession

Community Psychiatric Nurse (CPN) 7

Doctor 4

HCPC (Social Worker or Occupational Therapist) 3

Job Setting

CMHT 11

Memory Service 3

Settings of patient/client and carer contacts

Outpatient clinic 7

Patient/client's home 14

Care home	12
Hospital	11
Years of clinical experience	
0-3 years	5
3-10 years	3
10+ years	6

**Table 2. Personal Experiences of broadly defined Advanced Care Planning (ACP) (n=14)**

Personal Involvement in making Lasting Power of Attorney (LPA)	- 2
Experience of someone close making a LPA	- 6
Personal experience of making an Advance Decision (AD)	- 1
Experience of someone close making an AD	- 1
Personal involvement in making a Statement of Wishes	- 4
Experience of someone close making a Statement of Wishes	- 2
Any aspect of ACP – overall total	9

### **Knowledge and Experience**

Nine participants reported personal experience of aspects of ACP, broadly defined (See Table 2). Six had discussed their own future, ranging from informal to specific planning:

I've already told my friends like if I get dementia what kind of things I like, 'Vogue' magazines that I could just flick through...make sure I'm not cold, you know, put a cardigan on me (CPN)

I do have an Advance Decision...if anything ever happened to me in a road traffic accident ... I had a brain injury or something, I would rather be 'let go' (CPN)

Nine participants knew someone close to them who had engaged in ACP in some form, prominently arranging a LPA (n=6), although such discussions had not always been easy. Six participants had experience of facilitating ACP discussions in previous health and care employment settings.

All 14 participants reported some knowledge of ACP, although the depth of this varied; most thought this needed improvement before they would feel totally confident in facilitating discussions. Of six participants who seemed most confident in their understanding of ACP in general, they acknowledged gaps in their knowledge, centering on legalities, processes, and documentation:

I don't know the ins and outs of the law properly...the exact way you get appointed a LPA, I'm not exactly 100% sure...but I know I could advise them about why it's important...and the risks versus the benefits of doing it (Doctor)

Others acknowledged their more limited understanding and feared questioning:

I don't think I really know enough to actually do it... (the) relative might even have more advanced knowledge and questions they want to ask; I might not be able to give the answer (CPN)

Only four participants had received ACP training, for one this took place during a post-graduate palliative care course.

Despite this, participants largely agreed that any practitioner such as a care coordinator could engage in ACP discussions although some thought that hospital staff were generally better geared to such discussions than themselves. Participants thought that this would need good

communication skills, sensitivity, empathy and an understanding of the ACP process, including possible legal costs for LPAs. Others felt more specialist skills were required, especially about ADs:

If the Advance Decision (AD) is about some medical treatment or withdrawal of treatment, a bit more understanding and knowledge about that specific condition...the prognosis of that condition with and without treatment. (Doctor)

However, one participant expressed greater confidence in their own abilities:

... you don't have to have specialist skills, but if you get a bit of background...general skills (CPN)

Despite these uncertainties, 12 of the 14 participants considered ACP highly relevant to people with dementia and carers:

... it couldn't be more relevant to a patient group...we know that their capacity gets affected later on in life as their dementia progresses, so being able to make plans early on and helping them do that can really help them later on (Doctor)

It's hugely relevant...if these questions aren't answered when people can make these choices, in time then potentially they're gonna be answered by somebody else...they might not share that exact same view (HCPC registrant)

... it just kind of gives them a bit more guidance and support...that they feel that, 'I am actually following their (relative with dementia) wishes' ...they're supported in that (CPN)

### **Use of ACP**

Overall, there seemed to be wide variation in the methods and depths to which the participants reported discussion of different element of ACP (see Table 3).

#### **Table 3. Use of ACP (n=14)**

Discussion of/ Signposting to Lasting Power of Attorney (LPA) - 14

Further input on LPA - 4

Discussion of/ Signposting to resources on making an Advance Decision (AD) - 1

Further input on AD - 2

Discussion of/ Signposting to the making of a Statement of Wishes - 2

Further input on Statement of Wishes - 12

Discussion of / Signposting to information about End of Life care discussions - 0

Further input on End of Life care discussions - 1

### **Providing information and Signposting**

For the majority of participants, the extent of their engagement with ACP consisted of noting whether a LPA existed or was wanted. If required, they provided some information and signposting (providing contact details) to other agencies, especially the Alzheimer's Society – a national resource, law and advice centres, carers' groups, the internet (to download forms) and recommendation to contact a solicitor, all for either further information or support in making plans. All 14 participants reported signposting:

Usually I would just print something off for them to read, Alzheimer's Society, ...say that "You can go to the Citizen's Advice or Age UK, you know for help with the form"... nowadays we assess, signpost and discharge (CPN)

However, signposting was not always seen as sufficient. A minority of participants reported referring on to other team members for help with drawing up a LPA, despite the views of others in the team that they generally just offered signposting:

I would pass them to someone more experienced (CPN)

I tend to refer them to others in the team (HCPC registrant)

There appeared different approaches to discussing the future with clients and their families ranging from reactive to proactive:

I have heard people say ‘I want to die at home, I don’t want to die in hospital’, things like that; yeah...I wouldn’t bring the subject up. I would just let the patient or the carer tell me (CPN)

I haven’t sat down and chatted with people about where they want to see their care going or their last wishes and those kinds of things (HCPC registrant)

Some examples were provided of discussions directly with a person with dementia. One such an example, covered a case when the person’s wishes to remain at home were expressed:

We have been through, with him and his wife the kind of reasons why someone may need to go into a care home, but, but how this could hopefully be avoided in their case...in the event he (becomes) more seriously impaired cognitively, he wants palliation for any physical symptoms, rather than in and out of hospital...he is very reluctant to go into a care home. (Doctor)

However, ACP discussion might be confined to discussions with family members:

I have had no discussions with the patient directly (CPN)

Many agreed that such statements of wishes were often discussed, although not necessarily in a formal manner and therefore potentially not placed on any record:

We will very often discuss as things go down the line, you know, “Where do you want to be, who do you want to look after you?”, that, that sort of thing. (Doctor)

They were thought comparable with crisis planning by some:

We are so often crisis managing...well of course a crisis plan is a statement of wishes as well, because it’s how they want to be treated in their next crisis if that were to happen (HCPC registrant)

One explanation for the lack of discussion was that the ability to draw up LPAs had already diminished by the time some people with dementia reached secondary care mental health professionals:

Sometimes I think we catch it a bit too late, I think and that's still a problem. (CPN)

It is very rare that I am actually involved before they have lost capacity (HCPC registrant)

It was particularly evident that participants reported far fewer discussions about LPAs regarding Health and Welfare decisions, than LPAs covering finances. As one participant noted, having a LPA for property and financial affairs could seem immediately helpful for carers:

Even if you are married for 60 years and you lose capacity, if you don't have a joint bank account, your wife can't access any of your money for you unless you've appointed her as your LPA or unless she goes to court and pays £2000 or whatever and has a six month hearing (Doctor).

Most participants demonstrated far less knowledge of ADs than of LPAs. There were many misunderstandings of these and uncertainties. Some assumed these encompassed wishes for treatment, decisions about care homes, or were for individuals with no next of kin. Others questioned the scope of ADs:

I don't know if it's fully legal. (CPN)

Can you do them with carers? (HCPC registrant)

Almost all participants had difficulty reporting any examples of ADs in current practice, which was not surprising considering their lack of knowledge in this area:

I think I have told people about them, but no, I don't think I have, and I'm not sure why (Doctor)

It's just not on the agenda...I might have seen one or two people who have made an Advance Decision (CPN)



In most cases, examples provided were from work with adults with functional illness. Apart from one doctor who sometimes worked in another service setting, ADs were not discussed or used.

Of all participants, doctors indicated a slightly greater understanding of ADs but seemed reluctant to raise them with people with dementia or carers. Reasons were largely attributed to AD's abstract and hypothetical nature, difficulties in predicting the future, and how one might feel in the future:

... there are, you know, hundreds of possible decisions that could be made about their care in the future...far down the line and quite speculative and I think I couldn't possibly cover all of them and so I don't really cover any of them (Doctor)

Unsurprisingly, most professionals, including all the doctors, felt that they did not have the necessary skills to formulate ADs alone and that other professionals were better suited to this task.

### **Inhibitors of Discussion**

Many participants acknowledged the sensitivity required to engage in conversations about the future with people with dementia and carers. For some, the risk of causing further upset meant they did not broach the subject of future planning:

... people are worried enough getting a dementia diagnosis, but then to think, you know, "Well you're saying, well I shouldn't go to hospital?"...because people get sick and what do we think? We think we need the hospital...I think that, it's just worrying the person...I don't want to cause any more grief (CPN)

In contrast, one participant confessed being surprised how willing and able some people with dementia were to discuss their future:

Somebody, maybe an older generation who is coming to the end of their life, might want to talk about these things because they know they are in a different stage of their life...they might not be as difficult to that person as I perhaps thought they could be (HCPC registrant)

Participants reported that occasionally, it was clear that discussion about the future was being avoided for optimism or fear:

It's kind of thinking to the future, thinking to when they'll be in a less good place than they are now and some people shy away from doing that (Doctor)

Upon reflection, during the interview some participants expressed regret for not initiating such discussions:

It's much easier just to not have that conversation, which is terrible...we should be the people having the uncomfortable conversations (Doctor)

I just feel bad not having the discussion with, you know, the person themselves...I think it's still important (CPN)

## **Service Influences**

Service influences, such as resource availability, the remit of services and job roles and documentation systems, appeared to influence the extent and depth of ACP practice at superficial level but also more deeply. Many participants simply cited a lack of resources as impeding ACP discussion, with a 'lack of time' the most common barrier, due to competing role demands:

I just wish we had more time...it's something that isn't addressed as it should be really, because of all the other competing issues (HCPC registrant)

There is often a focus on risk and reducing risk and avoiding risk...sometimes it's not the most pressing of things to be talking about (Doctor)

The structure of service provision was felt by many participants to have a bearing on this. One memory service professional described their service's remit as being time restricted but thought that as the CMHT had the capacity for prolonged interventions with some patients, potentially ACP could fall within the latter's remit.

Many indicated that organisational imperatives, such as rapid assessment and case closure, limited the depth of ACP engagement possible:

With the sort of more rapid turnover of patients and the lack of kind of continuity in many sort of cases, it's more difficult than it was in some ways...our patients...are sort of passing through our team (Doctor)

It used to be, feel easier to do some of this work a long time ago (CPN)

It's specifically not in my job description (CPN)

It's not my role to, to get the actual (LPA) process going (HCPC registrant)

Another participant questioned the funding for ACP activity:

...there is a possibility that it wouldn't be seen as core business...I don't even think that end of life care is on the dementia pathway, which is shocking to me...in some ways it's become almost invisible...having all of these amazing services, it has actually made it more fragmented and it means that it's nobody's business (CPN)

Others positively supported the idea that their jobs should have more ACP focus and felt capable of this.

The recording of ACP discussion was reported to be predominantly undertaken in progress notes on the service's electronic databases. However, there was some confusion about where exactly this subject should be located. On some occasions, such information was shared within the team and with GPs after initial assessments or care reviews and with care homes if

seemingly relevant. No participants had access to an IT system to view or upload any ACP discussions, although many considered that this would be beneficial.

Although all participants in theory could assist in arranging a LPA and witness the documentation, only two doctors had done so. Reflecting their anxiety noted in other themes, others worried that this was outside of their domain:

I have never documented it or never signed it...I wouldn't want to put my registration at risk (CPN)

## **The Future**

Most participants envisaged changes in practice to address ACP further with patients and provided indications of how these could be adopted. Twelve wanted more general training in ACP or of an aspect of this, the process or legalities. Many advocated 'training' in the form of team discussion. Others desired training from specialists that seemed to be more skills based:

(from) the palliative care team...or us even to spend a day at a hospice...I would like to watch other people do things...they're experts at talking about death and dying (CPN)  
preferably a solicitor...they actually know what the framework is (CPN)

Several participants considered that some sort of framework or flowchart would aid their understanding of the general ACP process and its aspects; adding that this might be a reminder to facilitate discussion:

... in things that I do have knowledge about, if I, If I was sort of given, given a framework to do that in, I would very happily do it...(if) there are areas that should be covered like social care, medical care, you know finances whatever, um, then I can go through that (Doctor)

The addition of 'ACP' to the service's assessment template and a regular 'slot' to discuss these in MDT meetings was proposed.

Public information on LPAs was not viewed as particularly ‘user’ or ‘dementia friendly’. Better good quality leaflets to offer patients about ACP in general and the process for drawing up LPA, ADs and statements of wishes were considered by many to be helpful:

We could just give information out to people to be able to reflect a little bit more on at the end of the assessment...to have something about advanced care planning...it would make it a lot easier for people (HCPC registrant)

As noted, many participants wanted more of a team focus on ACP however, some felt some further personal motivation was required:

Pushing yourself, just making sure those conversations are had, even though they might be difficult (HCPC registrant)

## **Discussion**

There are four main limitations to this research. Firstly, most of the 14 participants were CMHT professionals, with only three from Memory Services and in one locality. Secondly, existing rapport with participants may have either influenced or dissuaded participation. Thirdly, the method of recruitment, where professionals were asked to contact the researcher if interested in participating, is perhaps more likely to influence participation by those with either knowledge of or an interest in ACP, than those without. Lastly, participants reported their ACP practice; it was not verified by observations or case records. Nonetheless, few studies have focused on the perceptions of community mental health professionals about ACP in contrast to numerous studies of it in other locations and services (van der Steen and Goodman 2015).

Following the National Dementia Strategy (DH, 2009) memory services have increased and with incentives for primary care, this may have prompted earlier diagnoses of dementia.

However, this present study indicates that there appears to be only moderate emphasis on ACP among CMHT and some memory service professionals. The Prime Minister's Challenge (DH, 2015) recognised that care coordinators (a role taken by many CMHT staff) may play a central role in enabling discussions about planning future care, but this present study did not reflect this encouragement.

The purpose of this exploratory study was to investigate whether and how NHS community mental health professionals are providing opportunities for people with dementia and their carers to engage in ACP. Overall, few participants felt skilled in ACP or used the intervention in any depth, on a regular basis. There appeared to be a general lack of knowledge and confidence among approximately half of the participants interviewed and those that possessed some information, acknowledged this was partial. Ten professionals recalled no ACP training and like earlier studies (Brown & Jarrad, 2008; Dempsey, 2013; Nicholas et al., 2014; Poppe et al., 2013; Robinson et al., 2012) participants thought they needed specific training before they would feel confident in facilitating ACP. As with Brown & Jarrad's (2008) study of patients and carers, and Robinson et al.'s (2012) study of professionals, misunderstandings were reported of terminology and legislation. Interestingly, although nine of the 14 participants recounted some personal experience of ACP, experiences did not necessarily translate to knowledge and confidence, particularly regarding LPAs and ADs. No participants identified a need to formulate ACP over time or to review, as suggested in guidelines (Fazio et al 2018), and there were uncertainties about where to document discussions and with whom these should be shared.

The depth of engagement in the ACP process for professionals varied. Beliefs such as role remit and the availability of resources appeared to govern the extent to which participants engaged with this activity. The predominant form of work touching on ACP was information

provision and then signposting to other agencies, sometimes combined with conversations that future planning would be good to think about or provision of some basic facts about ACP. The difference between information provision (Hoffman et al., 2013; Lewis et al., 2015; Manthorpe et al., 2014) and signposting (Robinson et al., 2012) may be miniscule. Other than information provision and signposting, as found by others (Denning et al., 2012), ACP did not appear to be part of routine community mental health practice among those interviewed. Although most participants in this present study reported some discussion about the future with clients, at least half acknowledged this was minimal, sometimes involving carers alone. Some related ACP to recovery planning and crisis planning. Again it seemed a matter of depth, whether such plans included goals of care, future care wishes, preferences regarding end of life, refusals of treatments, or discussions or plans to appoint others to make decisions. The data from this small sample indicate that ACP discussions do not take place regularly or cover all its possible areas and that feelings of discomfort are evident among several participants. Like Manthorpe et al.'s (2014) and Robinson et al.'s (2012) findings, mention of LPAs for property and financial affairs appeared more common than discussion of health and welfare LPAs. As Lawrence et al., (2011) found, ACP was often seen as someone else's role.

Reflecting Robinson et al.'s (2012) findings, there appeared to be several misunderstandings of ADs by many participants and their usefulness was questioned. They were not used in practice and participants reported no discussion of the potential use of ADs in community settings. ADs have been recommended for people with dementia, to avoid over-active treatment. However, no participant voiced such opinions; instead other reasons not to make ADs were expressed, such as the abstract and hypothetical nature of ADs. It was also generally felt ADs would be better facilitated by those working in physical care settings; echoing views that ACP generally was someone's else's role.

Insufficient resources, time and training, were highlighted by most participants, confirming others' findings (Denning et al., 2012) that these present barriers to ACP intervention. There was an emphasis on people moving through services, rather than having prolonged contact, thus inhibiting promotion of ACP, as seen in other studies (Gama et al., 2013; Lewis et al., 2015). Local funding or commissioning also appeared to impede further ACP practice since participants reported a lack of direction from managers about ACP. Documentation processes also were thought unsupportive of ACP. Fragmented care was cited in both the present study and by Denning et al.'s (2012) as potentially a barrier to ACP.

Most participants felt ACP was relevant to older people with dementia and expressed a need for further training in its various aspects and legalities. This contrasts with an earlier study's findings (Robinson et al., 2012) where the value of ACP for people with dementia was questioned. There appeared frank acknowledgment that occasionally ACP gets missed as professionals forget it. Unlike Poppe et al.'s (2013) study, the majority of participants did not use a framework to structure ACP conversations or discuss ACP formally but only a third concurred with the views expressed in Brown & Jarrad's (2008) study that a framework was needed to remind professionals to initiate and structure ACP discussion. Thus, this exploratory study confirms the European-wide study by Dixon and Knapp (2018) that policy emphasis on ACP is important but insufficient to ensure widespread provision of ACP support. Dixon and Knapp (2018) suggested that physician leadership and involvement are key to local adoption, but that the development of ACP practice needs to work with physicians' concerns on the one hand, while on the other balancing this against the risk of ACP becoming entirely physician-led, and limiting ACP in scope and time.

## **Conclusion**



The importance of people with dementia having opportunities to plan ahead with ACP is widely advocated. This exploratory study suggests that there is limited engagement with ACP by community-based mental health professionals and offers some explanations why. Although most participants viewed ACP as important for people with dementia and their carers, in practice the depth of ACP facilitation varied. For most participants, simple information giving and signposting to other agencies for further support, such as setting up a LPA, were the extent of their engagement with ACP.

Participants however recognised that more may be achieved regarding ACP with people with dementia and/or their carers and many provided illustrations of how this could be done, through receipt of training and peer discussion, availability of information, use of frameworks to structure the process, and ACP having more of a platform in clinical meetings. Further action research and audit regarding ACP may help give this subject greater priority and increase the consistency of professional responses and thus improve client and carer outcomes.

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